

February 7, 2011

State Legislators;

We would like to make a statement on behalf of our pediatric patients and their families for the coverage of Neocate/Elecare/Nutramigen AA (elemental formulas) by insurance providers.

Approximately 15-25 patients in our practice over the age of 12 years are prescribed elemental formulas annually. These children most frequently have a confirmed diagnosis of allergic eosinophilic gastroenteritis, eosinophilic esophagitis or short gut syndrome. The children with allergic eosinophilia usually present with clinical symptoms including poor weight gain, vomiting, diarrhea, blood in the stool, or food struck in their esophagus. Elemental formula is also prescribed for children with the diagnosis of short gut syndrome have had a significant amount of their intestinal tract surgically removed and have limited ability to digest and absorb nutrients.

Our children with eosinophilic allergy are prescribed a hypoallergenic diet, in which major food allergens are eliminated. If the child's allergic symptoms do not resolve with these interventions and /or their nutrition status can not be improved with diet, then an elemental formula is prescribed. For some children the allergy is so severe that food is completely eliminated and elemental formula is the sole source of nutrition and hydration

For the children with short gut syndrome, the elemental formula is usually the main source of nutrition and hydration and may be supplemented IV nutrition (or total parenteral nutrition-TPN) and a defined diet. The only other option for these children is all TPN which is much more expensive and carries significantly higher health risks.

Neocate/Elecare/ Nutramigen AA elemental formulas are necessary as a primary source of nutrition for children with allergy and short gut syndrome due to their unique elemental composition. They contain 100% free amino acids, and are milk proteingluten-and soy-free. No other formula components meet these elemental guidelines.

Our experience has been that many of our working families can not afford elemental formula. It would cost the average family \$11,680/ year to feed their child elemental formula. This puts a huge financial burden on families trying to provide appropriate medical care to their children.

If a family is forced to substitute with a different formula due to financial burden, the child is at increased risk for severe malnutrition, dehydration, and hospitalization. The average cost for one hospital day is \$2275. If a child requires parenteral nutrition (TPN) to correct malnutrition, the average national cost per day is \$1000. Insurance coverage for elemental formulas is a good preventive financial approach.

In light of such strong supporting evidence, we strongly support insurance coverage for these specialty formulas.

Thank you for your attention to this very important situation for children and their families.

Sincerely,

The physicians, nurse practitioners and clinical dietitians Department of Digestive Diseases, Hepatology and Nutrition Connecticut Children's Medical Center Hartford, CT 06106